

Progress through Partnership: The NINDS 2015 Nonprofit Forum
Natcher Conference Center
National Institutes of Health, Bethesda, MD
September 8-9, 2015

Day 1 **Tuesday, September 8, 2015**

- 12:00-12:30 p.m.** **Registration**
- 12:30-1:00 p.m.** **NINDS Director's Welcome**
Walter Koroshetz, M.D.
- 1:00-1:30 p.m.** **Patient Registries (Plenary)**
Joe Selby, M.D., M.P.H. (PCORI)
- 1:30-3:00 p.m.** **Lessons Learned and Case Studies in Patient Registries (Panel)**
Applying New Technologies; Social Media and the Consent Process

Moderators: Paul Gross (Hydrocephalus Association) and Dean Suhr (MLD Foundation)

John Wilbanks (Sage Bionetworks)
Geraldine Bliss (Phelan-McDermid Syndrome Foundation)
Lucie Bruijn, Ph.D. (ALS Association)
Joe Selby, M.D., M.P.H. (PCORI)
Erika Augustine, M.D. (University of Rochester Neurology Clinic)
- 3:00-3:30 p.m.** **Break**
- 3:30-4:30 p.m.** **NIH 101: Priority Setting, Decision making, NIH basics and Discussion**
Alan Willard, Ph.D. (NINDS)
- 4:30-6:00 p.m.** **Meet the Program Directors Session (followed by a reception)**

Day 2 **Wednesday, September 9, 2015**

- 8:30-9:30 a.m.** **An Overview of the NIH Strategic Plan and Discussion**
Walter Koroshetz, M.D., NINDS Director
Paul Scott, Ph.D. (NINDS)
- 9:30-10:30 a.m.** **Strategies for Stimulating a Basic Research Portfolio (Panel)**

Moderators: Ronald Bartek (FARA) and Ilene Miller, J.D., LL.M. (Hope for Hypothalamic Hamartomas)

Brad Margus (A-T Children's Project)
John Porter, Ph.D. (Parent Project Muscular Dystrophy)
Florian Eichler, M.D. (Leukodystrophy Clinic, MGH)
Kevin McNaught, Ph.D. (Tourette Association of America)
Laura Mamounas, Ph.D. (NINDS)

10:30-10:45 a.m. Break

10:45-11:45 a.m. Working with Government and Industry Partners on Translational Research (Panel)

Moderators: Amir Tamiz, Ph.D. (NINDS) and Susan Dickinson, M.S.
(Association for Frontotemporal Degeneration)

Steve Kaminsky, Ph.D. (International Rett Syndrome Foundation)
Robert Pacifici, Ph.D. (CHDI Foundation)
Bavani Shankar, M.B.A. (AstraZeneca)
James McArthur, Ph.D. (Cydan Development)

11:45-12:45 p.m. Partnering Effectively with Industry in Clinical Trials (Panel)

Moderators: Elizabeth McNeil, M.D. (NINDS) and Cynthia Rothblum-Oviatt, Ph.D. (A-T Children's Project)

Hubert Fernandez, M.D. (Parkinson Study Group)
James Kaiser, M.D. (FDA/CDER)
Katherine Beaverson, M.S. (Pfizer)

12:45-1:45 p.m. Lunch

1:45-3:45 p.m. Concurrent Breakout Groups: *Select two from the list below (Session 1 runs from 1:45-2:45 p.m. and Session 2 runs from 2:45-3:45 p.m.):*

- **Strategies for Stimulating a Basic Research Portfolio**
Moderators: Ronald Bartek and Ilene Miller
- **Working with Government and Industry on Translational Research**
Moderators: Amir Tamiz and Susan Dickinson
- **Partnering Effectively with Industry in Clinical Trials**
Moderators: Elizabeth McNeil and Cynthia Rothblum-Oviatt

- **NIH Strategic Plan Feedback and Discussion**
Moderators: Walter Koroshetz and Paul Scott

3:45-4:00 p.m.

Break

4:00-5:00 p.m.

Report Outs

5:00 p.m.

Adjourn